

HOSPICE Management ADVISOR

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Hospices expand outreach after San Diego school shooting

Counseling, bereavement skills come to the fore

On a recent typical sunny Southern California day, 1,900 students at a San Diego-area high school were making their way from one class to their next when a classmate randomly fired a .22 caliber handgun, killing two students and wounding 13 others. As a nation gasped at what seems to be an all-too-common story, students, parents, and teachers at Santana High School in Santee, CA, struggled to make sense of it all and grieve for two lives that were cut short without apparent reason.

Fifteen-year-old Charles Andrew Williams, whose slight frame and baby face belied the violence he is accused of wreaking on his school, is charged with a number of crimes related to the Mar. 5 incident, including two counts of murder in the deaths of 14-year-old Bryan Zuckor and 17-year-old Randy Gordon.

The details of the tragedy and accompanying images of wounded and distraught students are what captured the front pages of newspapers and lead television news broadcasts across the country throughout the week. But as the days passed and students returned to school, national attention turned elsewhere. Those left in the shooter's wake — not just those who were physically injured, but also those whose psyches had been shattered — face a long, difficult road as they begin to reconcile the world they once knew with the frightening world they have been thrust into.

Noreen Carrington, LMFT, director of bereavement and volunteer services for San Diego Hospice, was going about her normal duties of running the hospice's large bereavement program when word of the shooting came in that Monday morning.

At Sharp HospiceCare in nearby La Mesa, four employees whose children attended the school scrambled to locate their teenagers. "We heard about the shooting through word of mouth, and we spent much

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of the day waiting to hear from members of our hospice family to call and tell us their kids were okay,” says **Laura Grayson**, MSW, bereavement coordinator for Sharp HospiceCare.

Yet, as both organizations wondered how a tragedy like this could touch their community, they understood their responsibility to provide expertise in grief counseling. Officials at San Diego Hospice and HospiceCare didn’t wait for a phone call from school officials. Instead, they contacted the school Monday afternoon and offered their grief counseling services. After all, bereavement care and grief counseling are key components of the hospice mission, and those close to the shooting would definitely have grief issues to work through.

School officials accepted San Diego Hospice’s services, while the onslaught of volunteers prompted school officials to place HospiceCare counselors on a waiting list for on-campus counseling. That did not preclude them from helping, though. HospiceCare counselors were stationed at two of the local hospitals to provide counseling to family members of the injured who were being treated in the emergency rooms and surgery.

“The community really responded,” says Carrington. “On Wednesday, the first day students came back, there were about 200 counselors. We sent five.”

To the school’s credit, it had a disaster plan in place, and it was already in full gear when hospice counselors arrived, says Carrington. The plan included mobilizing teams to provide crisis intervention for students, parents, and teachers in need of it. Crisis counselors were placed in each classroom the Wednesday after the shooting, where they spoke with students and gave them an opportunity to share their feelings.

“We were there to support that plan,” says Carrington.

Focus on support, not therapy

Still, Carrington and other hospice counselors realized that their expertise was not completely compatible with the needs of students, parents, and teachers. For the most part, hospice bereavement programs deal with family members and friends who have had time to prepare for the death of a loved one. The focus of bereavement care is usually helping the bereaved begin the mourning process.

The focus is much different, says Grayson, when counselors are faced with those who are

grieving as a result of a sudden and traumatic loss. Counselors had to deal with the victims’ immediate needs. At Grossmont Hospital and Sharp Memorial Hospital, where seven victims were taken, including one victim who died, counselors met with family who were not only struggling to understand why the incident occurred, but to get information amid the chaos of both emergency rooms.

“What we saw was primitive, raw fear,” says Grayson. “Of course, there were the understandable questions of whether their child was going to be all right. Most were in utter disbelief. They just kept asking: Why?”

Recognizing the difference, counselors shifted their focus away from the way they normally address grief. Most of the time, counselors just listened and confirmed people’s feelings. “They were told: ‘This is a tragedy and you’re right to feel the way you do. What can I do to help?’” Grayson says.

Counselors acted as liaisons, linking families with medical staff to get updated information. They also provided a calm environment where families could wait, away from the crush of media trying to chase down the day’s big story.

The next day, a memorial service was held at nearby Sunrise Church to give residents of Santee an opportunity to pray and grieve for the dead and injured students, as well as for the remainder of the student body, which had been deeply traumatized by the incident. Three counselors and a social worker from HospiceCare attended the service as part of a crisis intervention team.

Looking for those in the fringes

All eyes were upon Santana High School the following Wednesday when students were scheduled to return to class. It was not business as usual, however, as students were allowed the day to talk with counselors and comfort one another.

Hospice of San Diego counselors were part of a platoon of volunteer counselors both in the classroom and roaming around campus Wednesday and throughout the week. Hospice counselors were stationed around campus to provide on-the-spot counseling for students who showed outward signs of struggling.

As Wednesday progressed, mourners and well-wishers built makeshift memorials of cards, pictures, and balloons where their two fellow students fell. As parents dropped off their children, they held on to them, reluctant to let go.

“A lot of kids were fearful of returning to school,” says Carrington. “There were a lot parents who were just as fearful. I saw a girl who was injured during the shooting come back with her mother. They arrived later in the day, and you could tell both were having a difficult letting each other go.”

It was moments such as this when Carrington and her colleagues were asked to step forward and help. The mother and daughter were ushered to a “safe zone” — a place on campus such as an unoccupied classroom or library — where they could receive counseling.

“We got them both to a safe zone, and the mother was able to feel better about leaving her daughter, and the daughter was able to go to some classes,” Carrington continued. “I saw the young lady later in the day. She was surrounded by friends, and they seemed to be supporting her. I saw such courage in these kids, it was incredible. The students were real good at taking care of themselves.”

Carrington and other counselors, however, kept a close eye out for students who were not getting support or who were in small groups where no one seemed to be coping well. “Our job was to look out for those on the fringe, those who didn’t have a support group to lean on or whose group as a whole was having a hard time.”

As in the frantic moments and hours immediately after the shooting, the focus had not changed. Counselors were still addressing immediate needs, says Carrington.

“This was not therapy; it was support,” Carrington says. “They were all trying to make sense of something that didn’t make sense.”

For teenagers, the incident made what is already a difficult time in life even more difficult. School is supposed to be a haven of sorts for teenagers, a place where they can measure themselves against the ebb and flow of life and emerge as individuals ready to go out into the world. The shooting, says Carrington, took that safe haven away and robbed them of a great degree of both their innocence and their longing for independence. So, while the vast majority of students don’t bear any physical scars, the emotional scars were deep and fresh that first day back.

In the classrooms, crisis counselors “debriefed” students by asking them to participate in group discussions or activities designed to get them to share their unfamiliar emotions. Some students were asked to write a letter to anyone of their choosing describing how they felt.

“I was told that every child was completely engaged in this activity and that many chose to write to the parents of the two students who were killed,” Carrington says.

Wednesday, Thursday, and Friday were a departure from normal school activities. School officials themselves were unsure when the school would get back to the business of teaching. “What I saw was the school taking things day by day,” Carrington says.

Meeting long-term needs

Although Santana High School has now taken on the semblance of normalcy, that outward appearance doesn’t mean the students, parents, and teachers are far enough removed from that fateful day to be considered healed.

“What we’ve seen in cases of traumatic loss is that four to six weeks later, you begin to see the true impact of what has happened,” says Grayson. “The initial shock that we feel when something like this happens protects us, but when the shock wears off, the feelings and emotions that have been held back begin to surface.”

That underscores the need for long-term care for children who continue to struggle. To help address victims’ long-term needs, HospiceCare has opened up its bereavement programs to students and school officials. The hospice recently launched a traumatic loss program designed to address bereavement issues following unexpected deaths, such as automobile accidents and suicide.

In addition, the hospice’s adolescent grief group was offered to students who wished to participate in group therapy with their fellow students and other peers who have lost loved ones unexpectedly.

“We would help these teens talk about loss — not just about the loss of other students, but the loss of trust and innocence,” Grayson explains.

The teen grief group is especially valuable to the long-term care of Santana students, says Grayson, because it centers around teenagers talking to other teenagers. “Teens use themselves so much better than they use adults,” Grayson adds.

San Diego Hospice will keep an ongoing presence on campus. Counselors, some of whom have become familiar to students, will visit the campus once a week to talk to students who voluntarily seek their help and to those who seem to be having difficulty coping.

Looking back, Grayson and Carrington have nothing but praise for the way their organizations responded and even greater praise for how school officials and the community responded so quickly to students' needs. The events of the week are still fresh in their minds, making it difficult to assess changes that would improve school access to their programs or make their own counseling more effective. But one lesson seemed to stand out: "In a crisis, everyone wants to do something," Carrington says. "We need to learn how to wait and listen, give what's needed when needed." ■

Not-so-new technology can help hospice

Hand-held computers and telemedicine top list

In this digital age where 12-year-olds pass notes in class using hand-held computers, it's a conundrum as to why hospices have been slow to embrace technology. Limited capital needed to acquire expensive systems can explain part of it, but it doesn't completely explain why commonly used technology still hasn't found its way into the mainstream of hospice care.

"Hospice is still a cottage industry," says **Tim Cousounis**, vice president of Jefferson Home Care in Bryn Mawr, PA, which includes hospice care. "It is still fragmented and made up of mostly small hospices that don't have the capital that would allow them access to technology."

Perhaps the very essence of hospice care — health care that relies almost solely on touch — prevents it from implementing technology into its low-tech, hands-on approach to patient care. After all, hospice care is a species of old-fashioned nursing care that many believe has been pushed aside with the advent of expensive gadgetry.

But hospice caregivers need not feel that way, says **Stephen Conner**, PhD, executive vice president of research and professional development for the National Hospice Association and Palliative Care Organization (NHPCO) in Alexandria, VA. Instead, certain types of technology should be seen as tools to help organizations be more efficient.

"Any system that makes it possible to spend more time at the patient bedside is good," Conner says.

With new technology emerging so quickly, hospices also face the challenge of having to discern between what is actually useful and what is simply technology for technology's sake.

The two factors that should guide hospices when choosing to update their technology should always be quality and efficiency. The technology should in some way improve care and help workers do routine tasks in less time, allowing them to spend more time on patient care, says **Calvin H. Knowlton**, PhD, CEO of Hospice Pharmacia, a pharmaceutical care consulting and medication distribution company in Philadelphia.

Both Knowlton and Connor say the use of hand-held computers and telemedicine is the most promising technology for improving hospice care. They can allow nurses to spend more time with patients, decrease the time nurses spend doing routine tasks, and speed up the exchange of information between clinical staff, patients, and physicians.

Real-time drug information

Hand-held computers, also known as personal digital assistants (PDAs), are nearly as popular as wireless phones. The term "Palm Pilot" has transcended the lexicon of gadget freaks into the mainstream. These devices have added a whole new dimension to the way people manage information. A husband can no longer wiggle out of missed appointments by claiming he simply forgot, when his wife can coordinate his schedule by easily downloading their scheduled appointments onto his PDA.

But as popular as this technology has become, the hospice industry is just beginning to find ways to use it. For example, Hospice Pharmacia is outfitting several hospices with hand-held computers that contain software developed by Numoda Corp. The devices will enable nurses to access patient medication profiles, request medication refills, perform pain medication calculations, and access step-care protocols in a wireless, real-time fashion.

If the trial works as planned, staff will be able to eliminate many cumbersome tasks, such as updating medication profiles used by a number of caregivers for one patient. Currently, the physician, nurse, pharmacist, and hospice all maintain separate profiles, a system that necessitates meetings and memos to communicate any additions or removals from the list. The new software and PDAs should allow a nurse to update the list on

her PDA and download the information to a central system that can be accessed by other staff and physicians who get the most up-to-date list.

The hand-held devices also permit nurses to collect and transmit data on patients' pain levels and associated symptoms. These applications provide for evidence-based decision-making at the point of care, patient pain management, and outcomes reporting, says Knowlton.

The hope is that the experiment will increase efficiency, reduce costs, and allow for measurement of pharmacotherapy outcomes in real-time. "Hospice Pharmacia's addition of wireless applications reduces the amount of time our nurses spend on pharmacy issues, allowing them more time for patient care," says **Susan Lloyd**, executive director of Delaware Hospice in Wilmington, one of two programs being set up with these devices.

"We hope it will make clinical staff more efficient, while improving our outcomes," says Cousounis, whose hospice is also participating in

the project with Hospice Pharmacia.

For now, staff will be performing routine tasks using their hand-held computers, such as getting prescription information and making prescription recommendations, says Knowlton. They will have access to a Hospice Pharmacia database that will allow them to make evidence-based decisions using available outcomes data for specific drugs based on the patient's current drug therapy and his or her disease. But Knowlton admits that all this is small potatoes compared to what he envisions the technology being able to do.

The NHPCO also sees promise in hand-held computers. The organization is working with Brown University in Providence, RI, to develop a data collection system that uses PDAs as the point of data entry. The hope is that hospices can collect satisfaction survey and outcomes data at the bedside, saving time that it takes to collect the data manually and enter it into a separate database. ■

Telehospice can boost access for limited staff

Test projects will measure effectiveness

Video cameras mounted atop computer monitors have been used by business and recreational computer users alike. Video conferencing allows offices in different cities to talk in real time and even permits grandparents to frequently see grandchildren who live hundreds of miles away.

That same technology also can bridge the distance between hospices and patients who live in distant, rural areas or who are urban shut-ins, experts say. Last year, researchers in Michigan and Kansas began studying the usefulness of telemedicine in the hospice setting.

Critics of telemedicine fear that the technology will lead to less care. Rather than nurses making face-to-face visits, telemedicine visits will replace home visits, they argue.

"I see telemedicine as something that will actually add care," says **Stephen Conner**, PhD, executive vice president of research and professional development for the National Hospice Association and Palliative Care Organization (NHPCO) in Alexandria, VA. "I believe the number of visits will not change, but the technology will increase access to hospice nurses."

Hospice of Michigan in Southfield and Michigan

State University (MSU) in East Lansing are participating in a joint project to study the use of telemedicine for Hospice of Michigan patients.

Researchers have been examining the use of interactive video technology as part of a care program for 40 Hospice of Michigan patients during a two-year period. The goal of the study, which is funded in part by a grant from the National Telecommunication and Information Administration, is to examine the use of technology in eliminating barriers, including geography and cost, to quality end-of-life care.

The Michigan project is part of a two-state study that will examine how the technology can improve hospice care. The University of Kansas is studying the use of telemedicine in Kansas with Hospice Inc. in Wichita, Hays Home Health and Hospice in Hays, and Hospice Services in Phillipsburg.

"We think that telehospice will play a role in enhancing hospice care by increasing the amount of service available to patients and lifting the pressure off hospice providers who are trying to provide greater access to care and relieve some of the costs associated with high-level quality care," said **Pamela Whitten**, PhD, assistant professor of telecommunications at MSU and lead researcher on the telehospice project in Michigan, when the project began last year.

Since then, Michigan researchers have collected a year's worth of data. Whitten says preliminary figures show:

- **Increased access.** Patients and caregivers used the system to keep in more constant contact with hospice staff. This was especially evident after hours, when patients and caregivers are often hesitant to call staff out of concern that a nurse will have to make a needless visit.

- **System used as triage tool.** Staff were able to cut down on unscheduled visits made in response to caregivers concerns. In some cases staff were able to talk the patient or caregiver through the problem, rather than having to send a nurse to the home.

- **Patient and caregiver satisfaction.** Both patients and caregivers indicated they wanted to use the service more.

For no extra charge (Medicare provides limited reimburses for providers who use telemedicine, and telehospice is not reimbursed by Medicare), patients will have use of a 13-inch television monitor with a camera mounted on the screen. The teams will be able to control the image of the patient using the keypad of the touch-tone phone to enhance the visual interaction. For example, the team nurse will be able to zoom in and take an on-screen snapshot of a medicine bottle held up by a patient or family member.

By today's technology standards, telehospice is relatively simple. It involves the use of standard telephone lines and interactive video technology, including a speakerphone, a tiny video camera, and television monitors. Hospice patients who are participating in the study will be able to call members of the hospice interdisciplinary team for a video consult. That allows patients and their caregivers 24-hour access to a nurse or physician.

If a caregiver is concerned about the labored breathing of a loved one, for example, he or she can dial into the system and point the small camera at the patient so a nurse or physician can evaluate the patient's condition. The clinician can then instruct the patient on the next step and evaluate whether a nurse should visit the home.

Telemedicine is nothing new to the health care industry. For example, since 1986, Rochester, MN-based Mayo Clinic has had a satellite-based, full-motion video system to unite its clinics with sites around the world. Since then, more than 300 clinical examinations involving all specialties have taken place by means of this system.

In addition to patient exams, telemedicine is commonly used to interpret electrocardiography, echocardiography, X-rays, and magnetic resonance imaging between remote sites.

Hospices have only recently voyaged into telemedicine. In May 1997, Kendallwood Hospice in Kansas City, MO, embarked on a joint telehospice project with the University of Kansas. This partnership turned out to be the genus of the telehospice project involving Michigan and Kansas.

"We wanted to see if using telemedicine in a hospice setting was feasible," says Whitten, who was a researcher on the University of Kansas-Kendallwood project.

Going on four years now, the experience at Kendallwood has shown that telemedicine not only has applications to hospice, but has promise in improving care and reducing costs.

Original thinking held that telehospice's greatest potential is in serving patients in remote areas. Routine telehospice consults could be provided in addition to scheduled home visits without having to subject nurses to additional long drives to patients' homes in rural areas. Urgent calls could be handled in a timelier manner.

When problems or questions arise, the hospice doctor, nurse, or social worker can use the telehospice equipment to see and talk to the patient and family, assess the situation, and respond more quickly than if he or she had to drive to the location.

For Kendallwood, which serves a high number of rural patients, the use of telemedicine made sense. The technology was applied to lessen the need for hospice workers to drive long distances for short visits and give patients immediate access to staff when a crisis arises.

Contrary to rural areas of Kansas, Detroit is predominantly urban and suburban. Yet, Whitten says, access to hospice care is still an issue in these areas. "There are neighborhoods in Detroit, for example, that are too dangerous for nurses to go into after dark," Whitten says. "There are access problems not only in rural areas, but in urban areas, as well."

Among the questions researchers are hoping to answer is how well telehospice will be embraced by patients, their families, and professional staff that provide care. More often than not, patients and their caregivers are elderly, a demographic that has been slow to adapt to rapid changes in technology.

Researchers hope to be able to measure the effect telehospice has on provider-patient interaction. For instance, they will look at what subjects are discussed using telehospice and whether the technology impedes or enhances open discussion with the hospice worker. ■

Accreditation takes on a whole new meaning

HCFA rule ties it with Medicare funding

With the Health Care Financing Administration (HCFA) granting deemed status to a few accrediting organizations, the once-voluntary process of seeking that accreditation can now be tied to HCFA certification, giving new importance to preparations for that scrutiny.

In 1999, HCFA granted “deemed status” to the Community Health Accreditation Program (CHAP) in New York City and the Joint Commission on Accreditation of Health Care Organizations (JCAHO) in Oakbrook Terrace, IL. The move allows these accrediting organizations to not only perform their own accreditation surveys, but also certification surveys that determine whether a hospice is complying with Medicare regulations. And gaining that certification is a prerequisite for receiving Medicare reimbursement.

When it comes to accreditation review, most hospice providers dread the microscopic inspection. They spend months preparing and breathe a sigh of relief after the reviewer has left. What if, however, the visit is tied to certification? While the stakes are greater and the anxiety heightened, the preparation strategy is similar: identifying areas of weakness and making necessary improvements.

Hospices could use some tweaking

Most hospices need a little tweaking when it comes to policies and procedures that reflect on quality and administration, says **Jerald Cohen**, MA, RN, president of CHAP.

In the past, the JCAHO has said the five following accreditation standards garnered the most Type I recommendations:

- Standard LD.7 — defining hospice services in written contracts;
- Standard IM.9.20 — documenting medication and medication allergies and sensitivities;
- Standard TX.2 — obtaining and updating physician orders;

- Standard HR.6 — assessing, maintaining, and improving the competence of staff members;
- Standard IM.9.13 — maintaining proper documentation of care planning activities in the patient record.

JCAHO declined to release its most recent list of frequent Type I recommendations prior to the release of the accreditation organization’s own publication this month. CHAP, on the other hand, cites the following areas in which it finds hospices are in need of improvement:

- **Supervision of nursing aides.** Nursing aides should be supervised once every two weeks, including written documentation in the patient record.

- **Plan of care does not reflect physician orders.** The plan of care should be updated with each change made by the interdisciplinary team and agreed upon by the patient’s physician.

- **Lack of bereavement care plan.** Documentation often does not reflect a thorough plan, one that begins before the patient dies in which each family member’s need for counseling is assessed.

- **Unclear or poorly written agreements with contractors.** Some contracts with outside providers do not include clear language stating the responsibilities of contractors

and those of the hospice, such as medical management of the patient.

CHAP standards are based on four principles, says Cohen: Structure and function; quality; resources (human, financial and physical); and long-term viability (planning, risk management, and innovation).

“Most problems are in the quality area,” says Cohen. “To get through a CHAP review, you have to have more than just policies in place. You can have the most beautiful policies and procedures manual, but if you’re not doing what your policies say you’re supposed to do, you’re not going to get a good review.”

Improve documentation

A common theme among these trouble areas is documentation, or, more specifically, the lack of it. It is important to remember that, as far as the reviewer is concerned, if there isn’t a written record, the tasks were never performed. From the broader quality perspective, proper documentation

‘You can have the most beautiful policies and procedures manual, but if you’re not doing what your policies say you’re supposed to do, you’re not going to get a good review.’

allows for better interdisciplinary communication and helps avoid unnecessary mistakes.

The top documentation issue, according to the joint commission, is the keeping of medication information. Nearly 27% of hospice organizations surveyed last year scored 3, 4, or 5 on Standard IM.9.20. Each standard is scored on a five-point scale, 1 being the best and 5 being the worst.

For a hospice to score a 1 or 2, its nurses must question patients and family about medication the patient is taking, both prescription and over the counter, and check the home for other drugs the patient or family may have forgotten to mention. When there are changes in physician orders, nurses should note the update in prescribed medication and dosage. Yet, the observations and changes communicated to the nurse often fail to find their way to the patient record.

Experts blame noncompliance on the volume of data that nurses must collect, which is made more difficult because they are working with a hand-written system. Documentation should be looked at as a chain of accountability. Using patient medication documentation as an example, the chain begins with the nurse who must ask the patient and caregiver about medications and prescription compliance. The next link in the accountability chain is a clinical manager who needs to monitor nurse behavior diligently and offer remedies for those who consistently fail to meet documentation standards.

Keep updated physician orders

Another common documentation problem is failing to update physician orders. Physician orders change regularly, as doctors react to the changing condition of the dying patient. These changes often are made verbally, with a written order expected to follow.

However, in the course of treating the patient, nurses often forget to follow up with the physician and get a written order. Or, perhaps, the written order is received but not placed in the patient record.

Both accuracy and timeliness are issues providers must be concerned with in dealing with physician orders. Across the hospice industry, providers are having difficulty getting their nurses not only to keep a complete collection of physician orders, but also to update the orders in a timely fashion.

The same problems are also seen in clinical staff's documentation of care planning activities,

which include communication with physicians and interdisciplinary meetings or discussions regarding patient care planning. The best way to ensure compliance is to perform routine audits of patient charts and to provide routine inservice training to stress the importance of this task. ■

Medicare errors total \$12 billion in 2000

Errors in Medicare billing cost U.S. taxpayers \$11.9 billion last year, according to the Health Care Financing Administration (HCFA). In March, the Office of the Inspector General (OIG) released its annual study of error rates in the Medicare program.

"This final report points out the results of our review of fiscal year (FY) 2000 Medicare fee-for-service claims," OIG officials reported. "Based on our statistical sample, we estimate that improper Medicare benefit payments made during FY 2000 totaled \$11.9 billion, or about 6.8% of the \$173.6 billion in processed fee-for-service payments reported by HCFA."

HCFA blames the errors on a wide range of reasons, from inadvertent mistakes to outright fraud and abuse. Since HCFA began tracking error rates in 1996, it has monitored Medicare payments and has instituted actions to limit errors, including working with provider groups to clarify reimbursement rules and impress upon providers the importance of fully documenting services. Additional initiatives on the part of Congress, HCFA, the Department of Justice, and the Office of Inspector General have focused resources on preventing, detecting, and eliminating fraud and abuse.

'Continued vigilance is needed'

HCFA officials say their actions have contributed to reducing the improper payment rate by almost half since 1996. "However, continued vigilance is needed to ensure that providers maintain adequate documentation supporting billed services, bill only for services that are medically necessary, and properly code claims," OIG officials said. "These problems have persisted for the past five years. Our recommendations address the need for HCFA to sustain its efforts in reducing improper payments." ■

MDs need support with suicide requests

A new study led by a researcher at the San Francisco Veterans Affairs Medical Center (SFVAMC) has found that most physicians whose patients request help in ending their life deal with these requests alone, absent any advice from or discussion with their colleagues.

Researchers interviewed 20 physicians in Seattle and San Francisco who had received at least one request from a terminally ill patient for help in committing suicide. The results, which were published in the March issue of the *Archives of Internal Medicine*, showed that half of the physicians had helped a patient end his or her life.

The most surprising finding is that doctors rarely discuss these often heart-wrenching suicide consultations with other physicians. “Most physicians who received these requests really dealt with them alone,” says lead author **Jeffrey Kohlwes**, MD, MPH, assistant clinical professor at the University of California of San Francisco and physician in general internal medicine at SFVAMC. “They perceived an unspoken code of silence on the topic amongst their colleagues,” Kohlwes says.

The doctors reported the most difficulty in coping with requests from patients who wanted to die because they felt their lives had lost meaning, not for reasons related to physical pain and suffering.

The researchers recommended that physicians who care for terminally ill patients take the following steps:

- **Improve their skills in managing pain and suffering.**
- **Learn to watch for and treat depression.**
- **Strive to communicate openly and clearly.**

Researchers also pointed to the need for the medical profession to support doctors by encouraging discussion of requests for help with suicide.

Although physician-assisted suicide is illegal in every U.S. state except Oregon, doctors who care for terminally ill patients receive suicide requests with some regularity. Some guidelines have been written to assist doctors in dealing with these requests, but there has not been much documentation of the different ways in which

doctors handle suicide requests from their patients.

Aside from its illegality, the topic of physician-assisted suicide is considered taboo among physicians, a perspective that dates back to a passage of the Hippocratic oath that admonishes physicians to “give no deadly medicine to anyone if asked.” A few of the doctors also said they were worried about becoming known publicly as the “local Kevorkian,” Kohlwes says.

The isolation experienced by these doctors creates a heavy emotional burden, Kohlwes says. Four of the physicians cried during the interviews, a response that Kohlwes says “seemed more related to a lack of processing their actions rather than any regrets over their actions.

“Somehow, the medical community needs to create an environment where these physicians can discuss their decision-making process,” he says, suggesting that physicians should try to avoid the moral debate over physician-assisted suicide and instead discuss the processes they use to handle these requests.

“Improving the professional dialogue will improve care, and hopefully obviate the need for many assisted deaths,” Kohlwes says.

Although physical and psychological suffering were reasons many patients gave for wanting to end their lives, some doctors said patients frequently cite more existential reasons.

“Many terminally ill patients feel that their meaningful lives are over because they are no longer able to do the things they love, such as interacting with loved ones, being active, and generally being in control of their lives,” he says. “Physicians reported that these existential cases were the most difficult for them to intervene in.”

The doctors in the study who felt most comfortable managing this existential suffering favored open discussions with the patient and tended to view their discussions with the patient as a therapeutic tool rather than an avenue to some other intervention, he said.

The good news, says Kohlwes, is that most requests for physician-assisted suicide can be successfully handled by treating either physical pain or depression. “Most physicians we interviewed used these requests as a warning flag to aggressively treat a patient’s physical discomfort, and in many cases they felt this was effective,” he adds.

Most doctors in the study reported treating their patients with antidepressants, which another study has shown to reduce terminal patient requests for suicide. ▼

Hospitals urged to adopt new end-of-life approach

Physicians can involve additional people in the care of terminally ill patients to ensure their quality of life doesn't deteriorate in their final days, according to a study by Mayo Clinic researchers. The study authors note physicians as a group may prolong end-of-life suffering with aggressive approaches to "cure" the patients' underlying disease rather than acknowledging the time has come to provide the patient with palliative care services.

However, strategies can be implemented to reduce the suffering of a patient by orchestrating a multidimensional approach to helping ensure the quality of life at the end. The special article, done for the Mayo Clinic Cancer Center Quality of Life Working Group, appears in *Mayo Clinic Proceedings*.¹

Before the 1900s, most Americans died at home, surrounded by their loved ones. Currently, as many as 60% will die in hospitals, and up to an additional 25% will die in health care-related facilities such as nursing homes. Physicians have had an ever-expanding role in the manner in which people die, with so many Americans dying in hospitals and other health care facilities.

"With modern medicine emphasizing genetic manipulations, high technology, and cure at all costs, we often neglect what was once the most sacred aspect of being a physician: alleviating suffering," the authors write. "Therefore, we contend that the approach to a person dying in the hospital must change from simply postponing death to focusing medical interventions on maintaining quality of life to the end."

The authors defined the term "quality of life" as the physical, psychological, social, and spiritual domains of health that are influenced by a person's experiences, beliefs, expectations, and perceptions.

The Mayo Clinic authors conclude their article: "We believe that the principles that have been so successful in improving the quality of

life for hospice patients must be adopted in hospitals and related facilities such as nursing homes so that suffering can be relieved where the vast majority of Americans continue to die."

Reference

1. Rummans TA, et al. Maintaining quality of life at the end of life. *Mayo Clinic Proc* 2000; 75:1,305-1,310. ▼

Caregivers need training and education

Despite feeling overwhelmed by demands on their time, Americans caring for sick or aging family members have a "tremendous thirst" for training and education, a new survey indicates.

"What we're finding — and this is news for most medical companies — is that caregivers are really the people who make the decisions and buy the products, and they want help," says **Paul Alper** of Alper Associates in Charlestown, RI. Alper conducted a survey of 1,254 caregivers, which was released in March during the annual American Society on Aging conference in New Orleans.

Alper conducted the survey in partnership with three major caregiver organizations on behalf of clients who make or market health care products.

The median age of caregivers in the survey was 55, most of them women. More than half help with bathing and dressing, and 40% help family members with eating and going to the bathroom. Half are spouses.

Nearly two-thirds of those surveyed said they want training in use of products that help with incontinence, care of fragile skin, and bathing. And among those who have had some training, 65% said they want more.

The survey also found that 87% of caregivers are the primary decision-makers and buyers of health care products. "Too many medical-product companies think that the drugstore is their

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customer,” Alper says. “In fact, caregivers — the people who buy and apply those products — are the real customers.”

With a database of about 3,000 caregivers, Alper also will provide a report to the state of Florida to help planners learn more about caregivers and their needs. California is the only state with a comprehensive profile of its caregivers, he notes. ▼

Advance directives ease family stress

A new study conducted by researchers at Oregon Health Sciences University (OHSU) in Portland reveals that family decisions to remove life support that result in the death of a hospitalized loved one can cause high stress levels for as long as six months.

Specifically, researchers observed families in which dying patients were unable to voice their own decisions near the very end of life. Investigators affiliated with OHSU’s Center for Ethics in Health Care and the School of Nursing conducted the research, funded by the National Institute of Nursing Research, a component of the National Institutes of Health. Results of the study were published in the March/April issue of *Nursing Research*.

The researchers studied 74 family members who had recently experienced the death of a relative in one of four large hospitals in Portland. The doctors and nurses involved in the cases also took part in the study. Researchers focused on hospital deaths because decisions to start and stop life support more often occur in hospitals. In addition to family and caregiver interviews, family stress was measured through standardized questionnaires used to gauge emotional impact following a traumatic event. Stress levels were measured during two time periods. The first period was one to two months following death of a loved one; the second period was six to nine months after the death.

Stress levels of all families in this study were extraordinarily high, the study showed. Family stress was similar to reports from people who had survived ferry and construction disasters, and was twice as high as the stress reported by people who had lost their home to fire. In addition, while study families’ stress levels began to

taper off, they remained high for as long as six months following the death.

While all study families reported high stress, for families of a loved one who had not provided a verbal or written advance directive, the stress levels following the death were far higher. In families that had verbal advance directives, stress levels were moderate after death. For families whose loved one had completed a written advance directive, stress was markedly lower.

Advance directives are instructions for care near the end of life previously given by a patient in the event that they are unable to communicate their own wishes in their final days. Currently in the United States, approximately 20% of adults have completed a written advance directive. In Oregon, the statistics are much higher. In another study of recently deceased Oregonians, 68% were reported to have a written directive.

For many family members who chose to remove life support from a loved one without a verbal or

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written advance directive, caregiver interviews revealed the decision often haunted them for weeks and months.

In contrast, many family members whose loved one had previously completed an advance directive reported a sense of peacefulness in doing the right thing. "It was all clear because we talked about it and it was all on paper," another study participant explained.

"This study shows that a lot can be done to not only improve care of a patient, but also to improve difficult end-of-life experiences for their family," says **Virginia Tilden**, RN, DNSc, FAAN, lead author in the study. She is professor of nursing at OHSU and is associate director of the school's Center for Ethics in Health Care. "This research shows that advance directives can lift a tremendous burden from families at the time decisions must be made. Writing down your wishes so that your family members have a clear guide to follow near the end of life will reduce the stress on those you love."

In addition to the need for important family discussions, OHSU researchers note the role nurses and physicians play near the end of life. "While better communication within families can do a lot to relieve stress, the study showed that communication and support by doctors and nurses profoundly impacts the experience of families," says **Susan Tolle**, MD, one of the authors of the study and director of OHSU's Center for Ethics in Health Care.

"Families emphasized the need for caregivers to be truthful about the possible benefits of life-sustaining treatments and not to offer false hope," she says. "Following family decisions to remove life support, it's important for caregivers to support family decisions to reduce the long-term feelings of guilt." ▼

Hospice leader vows patent law fight

Father **Angelo D'Agostino**, MD, is a Jesuit physician from Boston whose Nyumbani hospice in Kenya cares for 70 AIDS orphans but can only afford AIDS therapy for 12 of them. "I am sick and tired of funerals," he says.

D'Agostino has announced he will accept a recent offer of cheap antiretroviral drugs from the

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Cipla pharmaceutical company in Bombay, India, in spite of the threat of a confrontation with Kenyan patent law. His move comes amid growing pressure from organizations like Oxfam and Médecins sans Frontières on the drug industry, which they claim is keeping prices too high while many regions of Africa are being decimated socially and economically by AIDS and other diseases. It also comes as a controversial court battle brews between pharmaceutical companies and the South African government over generic drug importations.

The drugs nevirapine from Boehringer Ingelheim in Germany and lamivudine from GlaxoSmithKline (GSK) in London are two of the three drugs in the Cipla cocktail. They are covered by patent law in Kenya until 2010, but Boehringer-Ingelheim has already reduced the price of nevirapine by 80%, and GSK has announced price reductions of up to 90% in specific circumstances. These reductions will bring the price of the triple-combination AIDS therapy close to the \$350 yearly cost per patient quoted by Cipla.

Jean-Pierre Garnier, CEO of GlaxoSmithKline, says he agrees with campaigners that more has to be done to make life-saving drugs available in the developing world. ■